



August 2023

Child Care & Developmental Disabilities

Elevating the Voices of Ohio Families

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Introduction

Families in Ohio who have a child with a developmental disability face unique challenges when it comes to child care. These families often need specialized care for their children, which can be challenging to find and can often come at a higher cost. Little data exists on the needs of families who have a child with a developmental disability as it relates to child care. The insight provided by families on their experiences with child care, along with their communication preferences will provide guidance to child care programs and policymakers on how to best support families with a child with a developmental disability.

Through the creation of a survey, we engaged a diverse range of families from 76 counties in Ohio. We partnered with various Ohio organizations to have the survey shared within their networks and have performed interviews to ensure we understand families' needs and how best to reach them. Additionally, the survey was translated and made available in both Spanish and Somali. In total, we received 768 completed survey responses.

This work will have four areas of focus:

1. The overall impact of child care on a family with a child with a developmental disability
2. The process of finding child care
3. How families become aware of public benefits
4. Child care for children with developmental disabilities over the age of twelve



Literature & Data Review

There is limited published research, literature, or data in the child care space as it relates to families that have children with developmental disabilities, their unique challenges, and how it pertains to child care. The review of existing resources resulted in the analysis of six published pieces and one draft report.

Key Findings from Analysis of Existing Data & Resources:

1. Work needs to be done in the field to understand the needs and preferences of families who have a child with a developmental disability. This conclusion is evidenced by a lack of published resources. ¹
2. Child care providers rated Early Intervention Program/Help Me Grow, Child Care Resource and Referral Agency (CCR&R), County JFS Licensing Specialist, Local Public School District and Head Start/Early Head Start as helpful community agencies that provide support to meeting the needs of a child with disabilities. ²
3. Child care providers' confidence on caring for a child with a disability is linked to the needs of the child. ²
4. Child care providers need clarity on available resources to provide needed support to children with disabilities and processes required. ²
5. Families face barriers when accessing child care for their child with a disability. ^{1,2,3}
6. Families must make sacrifices to care for child with a disability by requiring increased needs from family and community resources and making job changes. ^{3,4}
7. Data shows that families who have a child with a disability more likely to experience job disruptions. ^{1,3,4}
8. Number of children with developmental disabilities is increasing, along with a correlation between economic disadvantage and disability status. ¹
9. Children with a disability are more likely to use a center-based child care provider. ¹

1. Costanzo, M., & Magnuson, K. (2019). *How does disability influence child care arrangements for young children? An examination using the NHES ECPP*. Children and Youth Services Review.

2. Project Open House Final Report (2023). *Developmental Disabilities Basic Support and Advocacy Grants Exploring Outcomes of Enhanced Child Care Payments for Children with Special Needs*. University of Toledo.

3. Bonitatibus, S. (2021, November 9). *The Child Care Crisis Disproportionately Affects Children with Disabilities*. Center for American Progress.

4. Government Resource Center. (2011, January 11). *Caring for Children with Disabilities in Ohio: The impact on Families*. YouTube.

Survey Process

DSACO has partnered with i3 Works, a data company out of Minnesota that specializes in working with non-profits, and assisted in designing our survey to help us understand families' needs regarding child care. Additionally, we used an internal employee to translate the survey into Spanish and hired a translation agency, MINT, to translate the survey into Somali. Prior to releasing our survey, we gained feedback and recommendations from Dr. Laurie Dinnebeil, Distinguished University Professor Emerita from the University of Toledo. (Please see Appendix 1 to view the survey questions.)

Focus

The survey is focused on the impact of child care on a family with a child with a developmental disability, how families become aware of public benefits, and child care for children with developmental disabilities over the age of twelve.

Survey Dissemination Efforts

Through various organizational partners, we invited Ohio families who have a child with a developmental disability to participate in the survey. Below is a list of organizations that shared survey information with their stakeholders:

Duration and Incentive

The survey was open from June 22, 2023, to July 11, 2023. Survey participants were invited to participate in a raffle to win one of 10 \$50 Amazon gift cards.

Survey Process

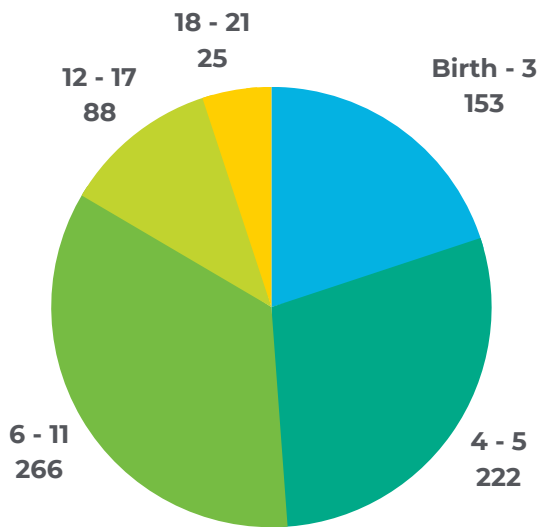
Participating Organizations

A Kid Again • Action for Children • Appalachian Family Center for Autism and Disability Resources & Education • Autism Connections • Bloom Free Store • Bottoms Up Diaper Drive • Boundless Health • Buddy Ball Grove City • Butler County Board of Developmental Disabilities • Casa Speech • Columbus Public Health • Columbus Recreation & Parks • Cuyahoga Special Education Service Center • Down Syndrome Association of Central Ohio • Down Syndrome Association of Greater Cincinnati • Down Syndrome Association of Greater Toledo • Down Syndrome Association of Northeast Ohio • Down Syndrome Association of the Valley • Easterseals Central and Southeast Ohio • Fairfield County Board of Developmental Disabilities • Fairfield County Family, Adult and Children First Council • Fairfield Developmental Disabilities Early Intervention • Flying Colors Preschool • Hamilton County Board of Developmental Disabilities • Hardin County Early Intervention • Hispanic Coalition • Hispanic/Latino Collaborative • Hocking County Board of Developmental Disabilities • La Mega Media • Lancaster Fairfield Community Action Agency • Learning Aid Ohio • Logan Elm City Schools • Lucas County Board of Developmental Disabilities • Marion City Schools • Marion County Board of Developmental Disabilities • Medina County Board of Developmental Disabilities • Miami Valley Down Syndrome Association • Nationwide Children's Hospital • OCALI (Ohio Center for Autism and Low Incidence Disabilities) • Ohio Coalition for the Education of Children with Disabilities • Ohio Department of Developmental Disabilities Services • Ohio Early Intervention • Ohio Head Start Association • Ohio State University College of Optometry • Ohio State University Nisonger Center • OhioKAN • Our Lady of our Guadalupe Center • Su Casa Hispanic Center • The Arc of Ohio • The Libre Initiative • Whitehall City Schools

Respondent Demographics

A total of 768 Ohioans who have a child with a developmental disability completed the survey.

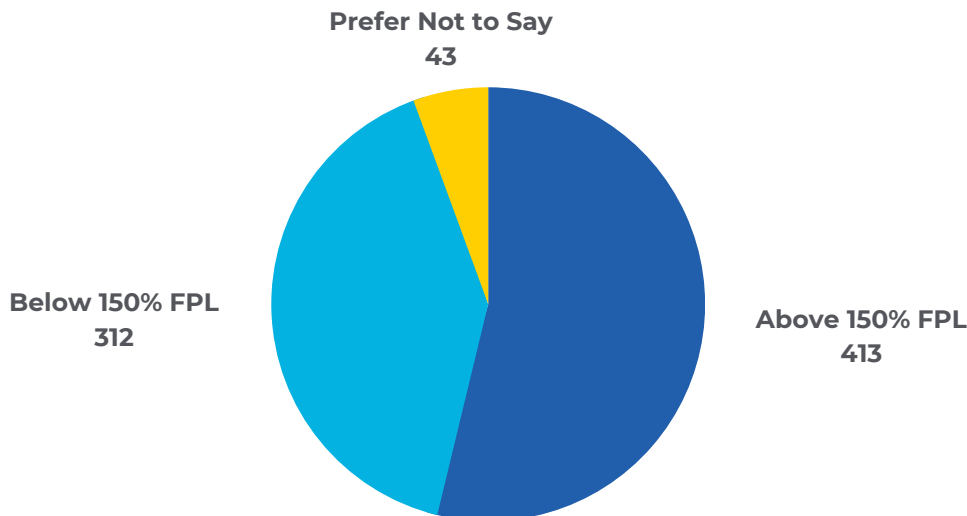
1. Age



3. Race

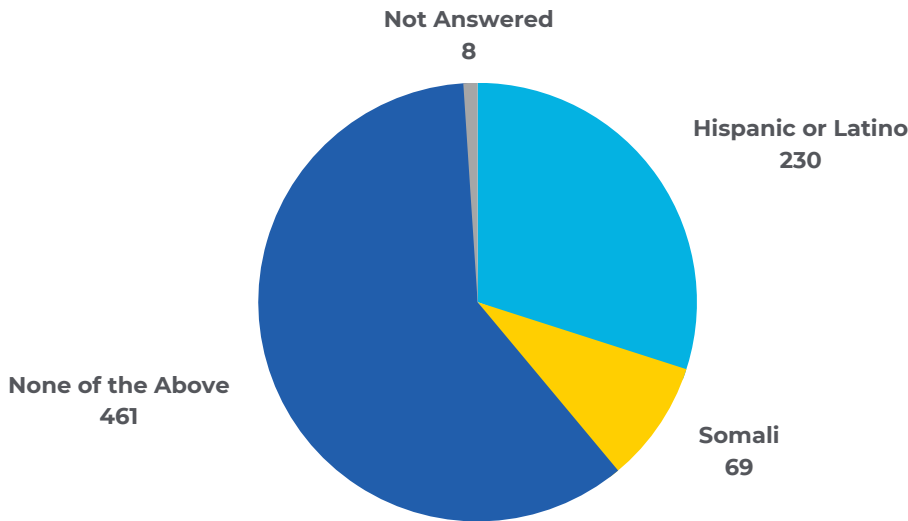
	#	%
White	530	69.01%
Black/African American	101	13.15%
Multiple races	35	4.56%
American Indian	27	3.52%
Asian/Pacific Islander	24	3.13%
Other	19	2.47%
Prefer not to answer	18	2.34%
Not answered	14	1.82%
Grand Total	768	100%

2. FPL Threshold

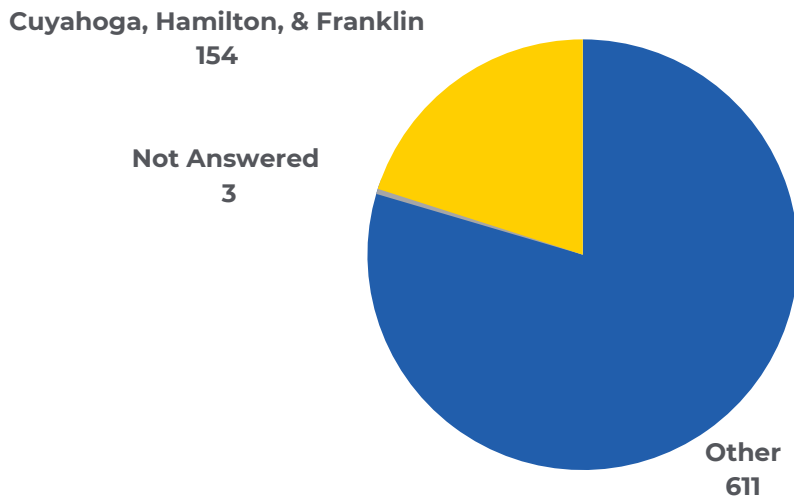


Respondent Demographics

4. Ethnicity



5. Geography by County



6. Education

	#	%
Less than high school diploma	24	3.13%
High school diploma or equivalent	116	15.10%
Some college or associate's degree	221	28.78%
Bachelor's degree	262	34.11%
Graduate or professional degree	123	16.02%
Prefer not to answer	18	2.34%
Not answered	4	0.52%
Grand Total	768	100%

7. Gender Identity of Respondent

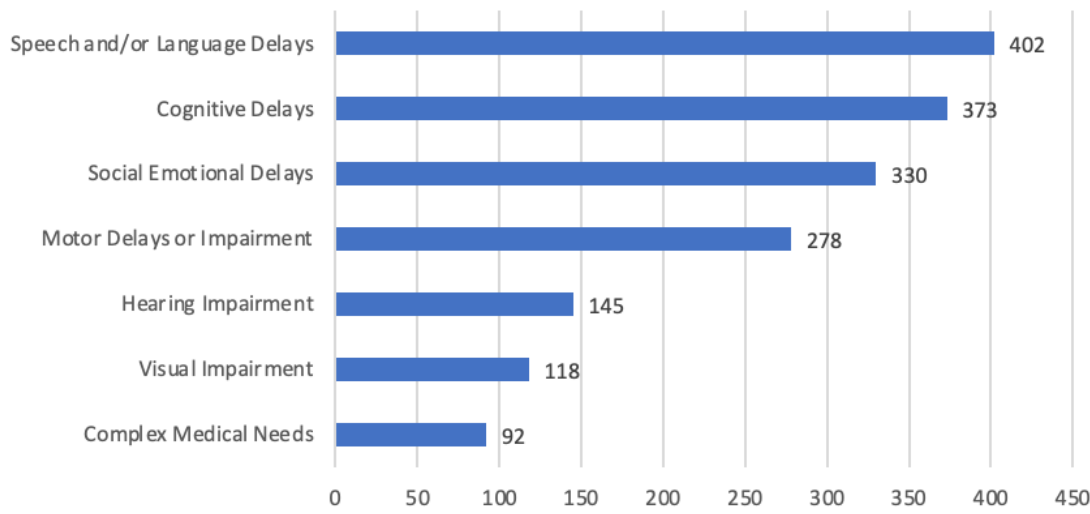
	#	%
Female	514	66.93%
Male	199	25.91%
Transgender/Gender non-conforming	30	3.91%
Other	12	1.56%
Prefer not to say	11	1.43%
Not answered	2	0.26%
Grand Total	768	100%

Respondent Demographics

8. Current Child Care Status

	#	%
My child with a developmental disability is in center-based child care.	225	29.30%
My child with a developmental disability is not in paid child care (i.e. they are either at home or with a family member), but I would like them to be. This is due to a lack of available or accessible options.	201	26.17%
My child with a developmental disability is in home-based child care.	194	25.26%
My child with a developmental disability is not in paid child care (i.e. they are either at home or with an unpaid family member) because I have decided not to do so for reasons other than lack of options.	148	19.27%
Grand Total	768	100%

9. Check the box or boxes that best describe your child's developmental disability.



Respondent Demographics

Additional Details:

1. Age of the child with a developmental disability
2. Self-reported Federal Poverty Level of family
3. Race of parent and/or caregiver who completed the survey
4. Ethnicity of parent and/or caregiver who completed the survey
5. Families surveyed represent 76 of 88 Ohio counties-- approximately 80% of respondents were outside of Cuyahoga, Hamilton, and Franklin County
6. Education of parent and/or caregiver who completed the survey
7. Self-reported gender of parent and/or caregiver who completed the survey
8. Self-reported child care status of the child with a developmental disability
9. Self-reported developmental disability of child by family

Survey Narrative

Each family who participated in the survey was asked to best describe their current child care situation by choosing one of the following options: "child is in child care", "child is not in child care but I would like them to be", or "child is not in child care by choice." From there, the survey used skip logic to ask a series of questions based on their response to this introductory question. (See Appendix 1 for more detail.)

The survey results are representative of one or more of the following categories of families:

Families whose child(ren) with developmental disabilities who are currently in paid child care

In addition to answering this question, families were asked to indicate whether they were in a center-based or home-based child care setting.

Families whose child(ren) with developmental disabilities were not in paid child care, but would like them to be

These parents indicated that, while they were actively trying to pursue child care, they did not currently have their child in a child care setting.

Families whose child is not in child care by choice, not lack of options

These families were asked to indicate why they chose to not have their child(ren) with a developmental disability in any paid child care setting.

All survey respondent groups were asked to complete questions relating to their awareness of the Special Needs Enhanced Rate, their communication preferences, and any other additional comments they wished to share.

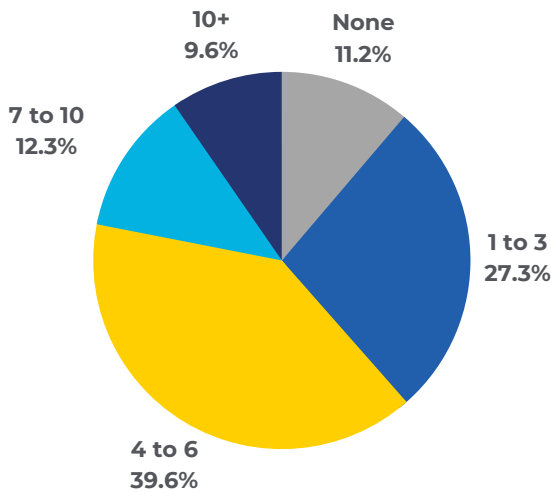
Survey Results

FAMILIES UTILIZING PAID CHILD CARE

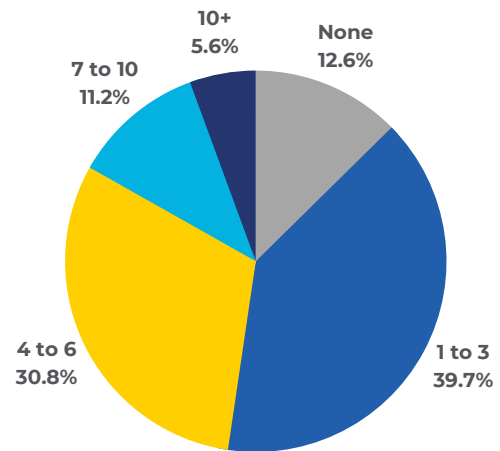
(home or center-based)

When looking for child care, approximately how many child care programs did you visit before making your selection?

Below 150% of FPL

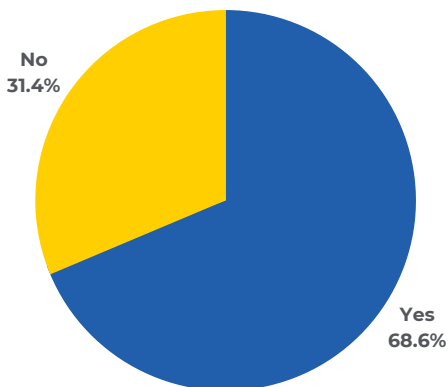


Above 150% of FPL

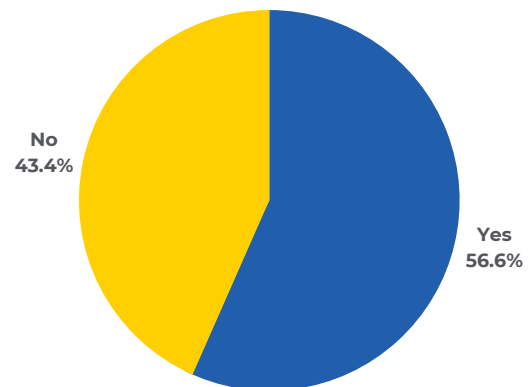


Were there any child care providers that communicated- directly or indirectly- they could not provide child care to your child due to factors related to their developmental disability?

Below 150% of FPL



Above 150% of FPL

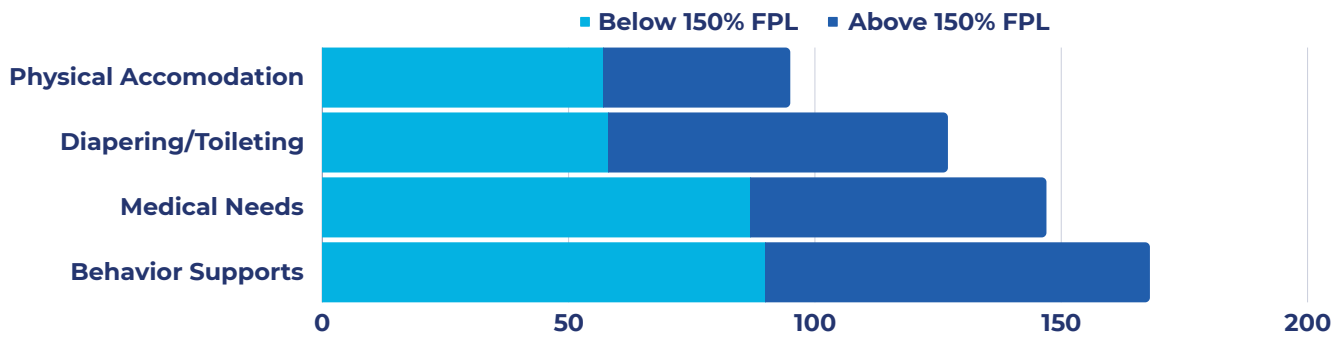


Survey Results

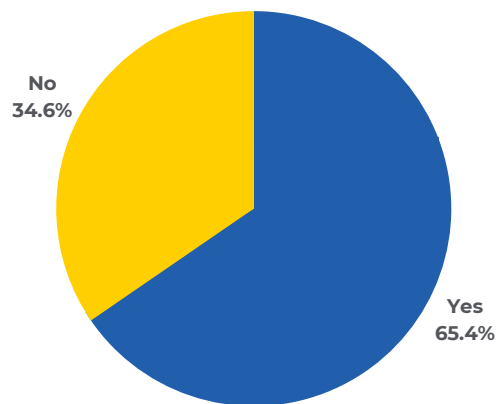
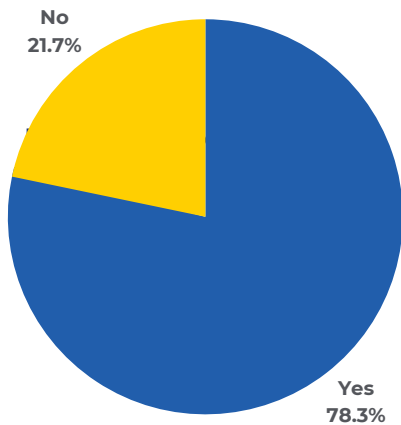
FAMILIES UTILIZING PAID CHILD CARE

(home or center-based)

What factors did child care provider(s) say they could not meet?



Have you ever had to switch child care providers because they were unable to meet your child's needs related to their developmental disability?



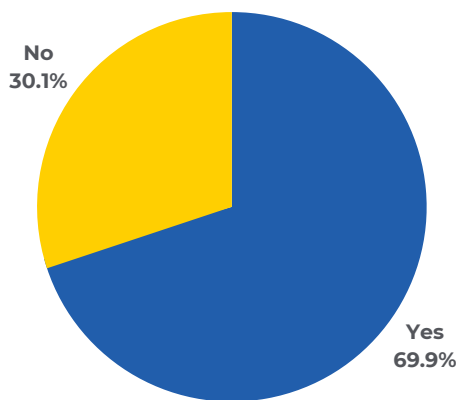
Survey Results

FAMILIES UTILIZING PAID CHILD CARE

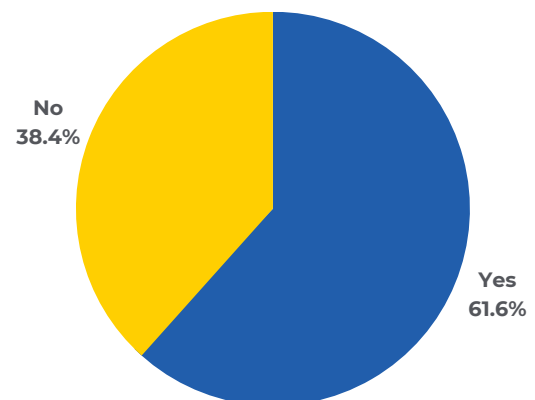
(home or center-based)

Have you ever experienced any perceived discrimination or negative attitudes from child care providers or other parents because of your child's developmental disability?

Below 150% of FPL



Above 150% of FPL



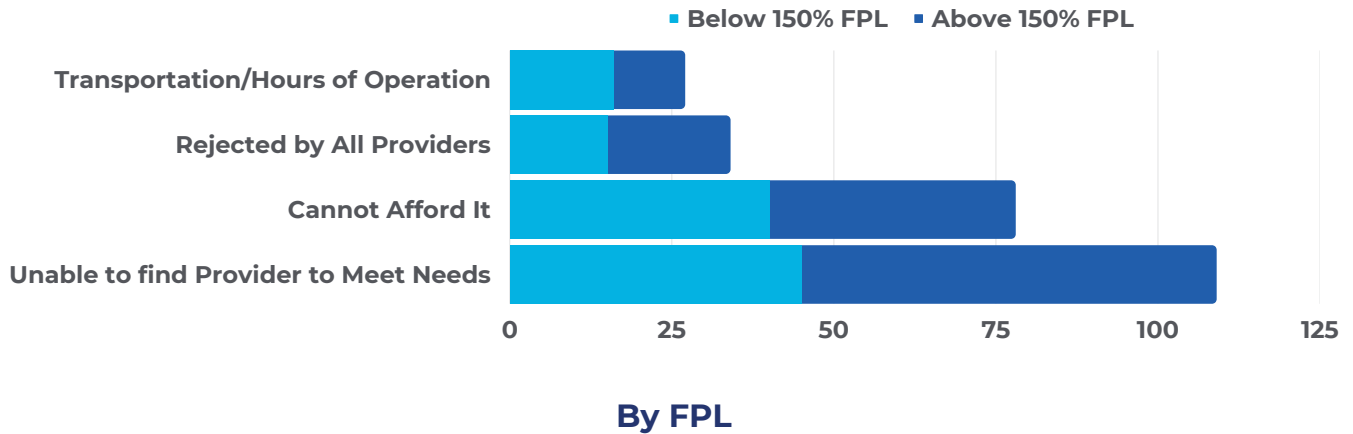
Notes:

- More than 60% of families with children in paid child care indicated that providers had communicated to them that they could not provide child care due to factors related to the child's developmental disability. Providers were most likely to indicate they cannot meet needs related to behavioral support, followed by medical needs, diapering/toileting, and physical accommodation.
- More than 60% of families have experienced perceived discrimination or negative attitudes from child care providers or other parents.
- More than 70% of families indicated that they have had to switch child care providers because the child care providers were unable to meet their child's needs related to their developmental disability.
- Families with household incomes under 150% Federal Poverty Level were more likely to visit more child care programs

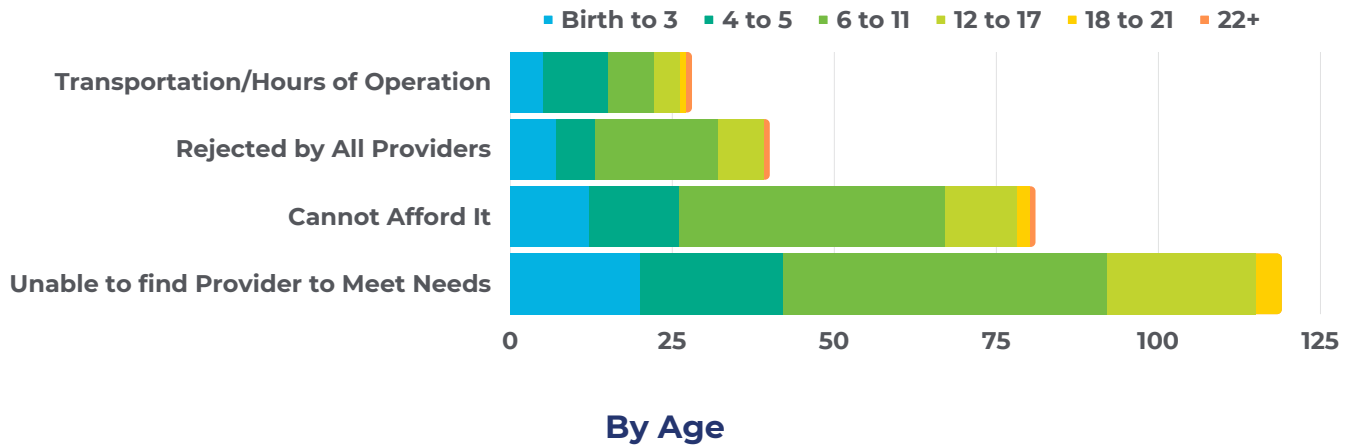
Survey Results

FAMILIES NOT UTILIZING PAID CHILD CARE BUT WOULD LIKE TO

Why is your child not in child care?



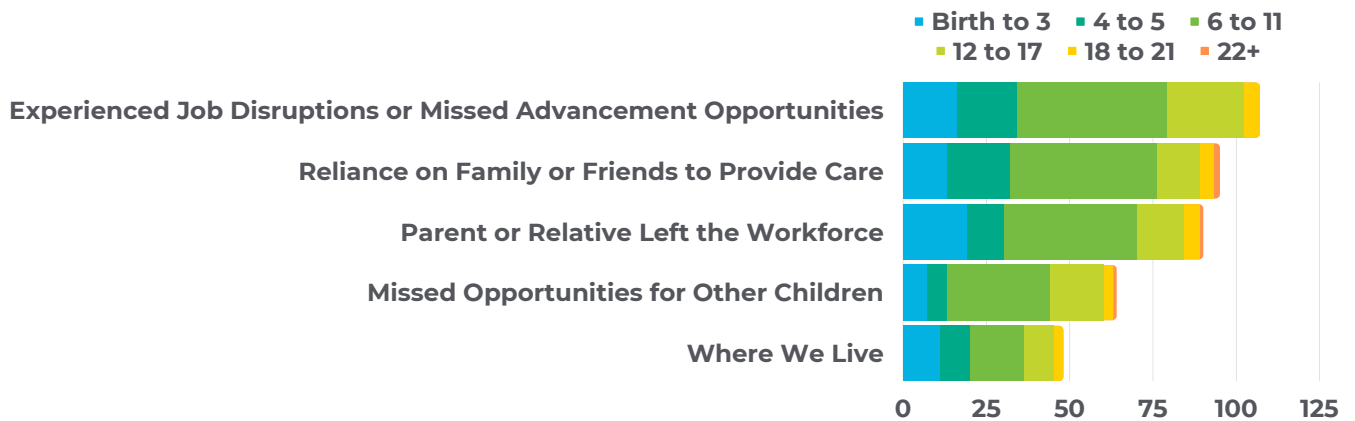
Why is your child not in child care?



Survey Results

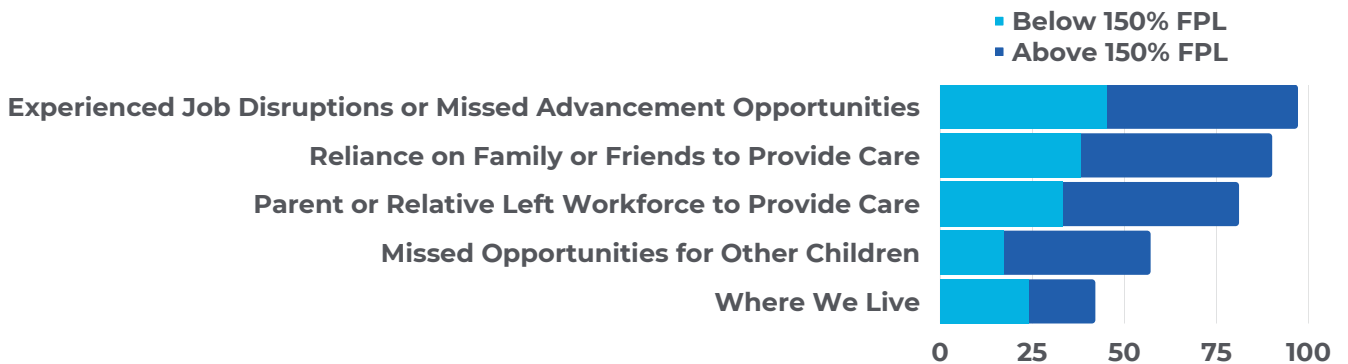
FAMILIES NOT UTILIZING PAID CHILD CARE BUT WOULD LIKE TO

How did the lack of child care impact you and your family?



By Age

Why is your child not in child care?

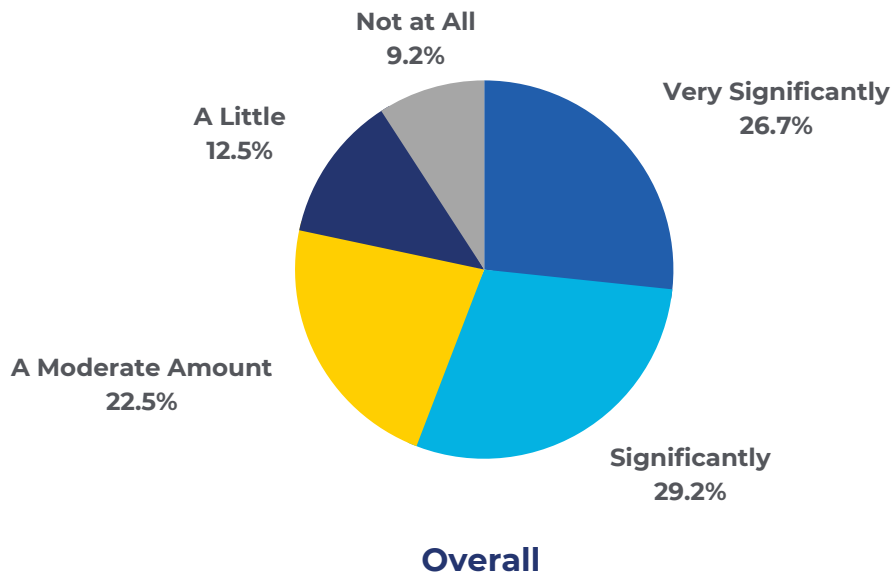


By Federal Poverty Level

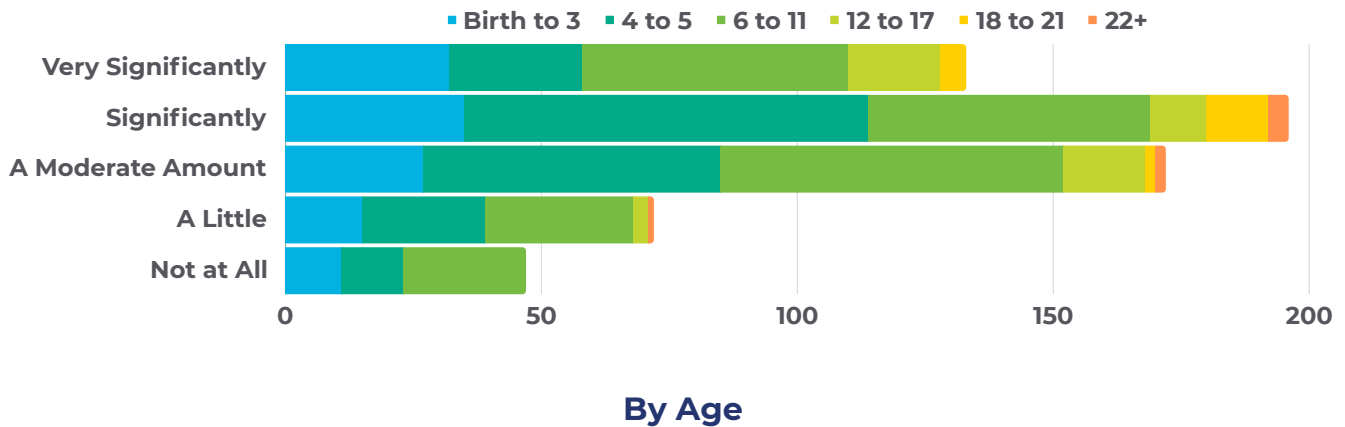
Survey Results

FAMILIES NOT UTILIZING PAID CHILD CARE BUT WOULD LIKE TO

To what extent has the need for child care impacted your ability to work a paid position or the position you have?



Why is your child not in child care?

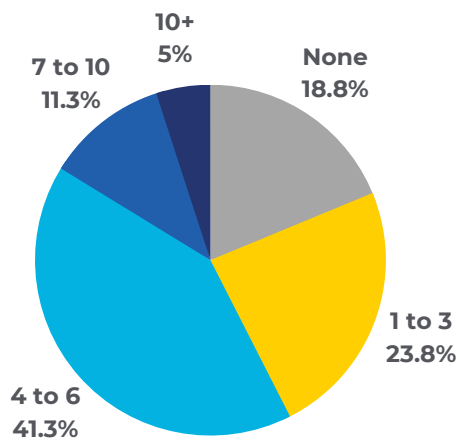


Survey Results

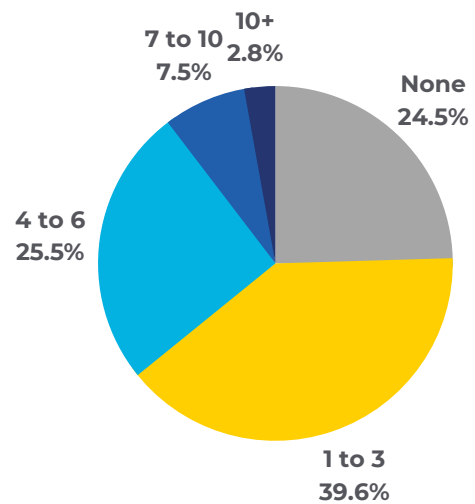
FAMILIES NOT UTILIZING PAID CHILD CARE BUT WOULD LIKE TO

When looking for child care, approximately how many child care programs did you visit before making your selection?

Below 150% of FPL

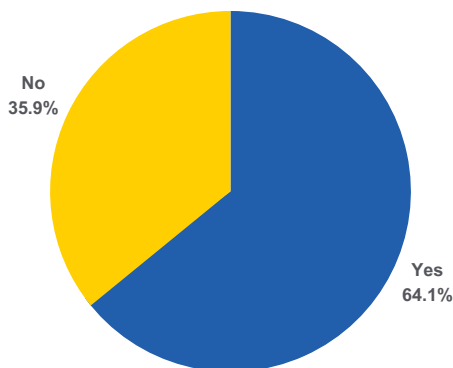


Above 150% of FPL

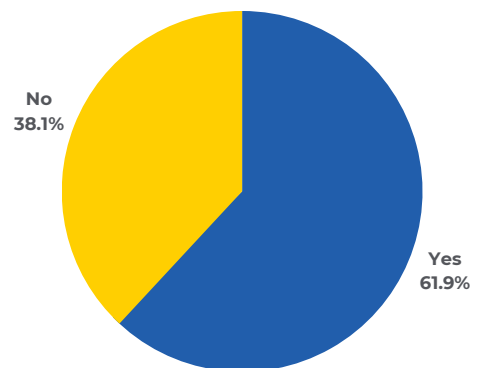


Were there any child care providers that communicated- directly or indirectly- they could not provide child care to your child due to factors related to their developmental disability?

Below 150% of FPL



Above 150% of FPL

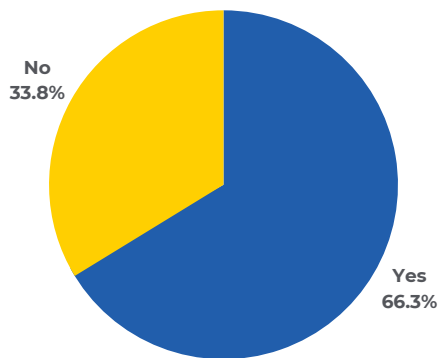


Survey Results

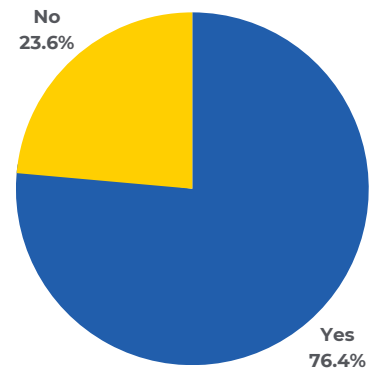
FAMILIES NOT UTILIZING PAID CHILD CARE BUT WOULD LIKE TO

Were there any child care providers you felt would be unable to provide care for your child due to factors related to their developmental disability?

Below 150% of FPL



Above 150% of FPL



Notes:

- More than 60% of families with children in paid child care indicated that providers had communicated to them that they could not provide child care due to factors related to the child's developmental disability.
- More than 70% of families indicated that there were providers they felt would be unable to provide care to their child due to factors related to their developmental disability.
- Families' most commonly cited reason why their child is not in child care is that they could not find a provider that could meet their child's needs associated with their developmental disability (62%). The next most common reason is that the family could not afford it (42%).
- Families were asked to select from a list how the lack of child care impacted their families, with more than half indicating they were impacted by job disruptions and missed advancement opportunities due to conflict with child care (53%).
- Other themes from this group of families include 1) feeling financially strained, forcing them to become one-income households or experience reduced income, 2) difficulty balancing work and child care, resulting in interrupted careers, limited professional growth, and missed opportunities for advancement, 3) increased dependence on family members that strains relationships and causes increased dependency on others, and 4) lack of child care options negatively impacts the child's learning and development opportunities as well as the family's overall quality of life.

Survey Quotes

*Kinship child,
no child care
assistance available.*

My child is not potty trained and child cares either don't take kids until they are potty trained or they don't take kids her age that aren't potty trained.

Between hospitalization and appointments, jobs have fired me or let me go.

We try to work opposite shifts, which negatively impacts our marriage.

(Child care) is a huge area of need for our family as well as many other families with special needs children that I know personally. The effects are astronomical and never ending.

I was a female entrepreneur who owned my own successful business. I had to close the business due to: 1) lack of child care options, 2) the many therapies and appointments, and 3) to be able to allow my child to participate in activities during the day.

Survey Results

FAMILIES WHOSE CHILD IS NOT IN CHILD CARE BY CHOICE

Themes of families who decided not to put their child in child care:

- Lack of trust in child care workers' ability to meet the child's specific needs and concerns about discrimination or bullying.
- Desire for consistency, routines, and specialized care that may not be available in child care programs.
- Concerns about the safety and well-being of the child in child care settings and worries about potential abuse or inappropriate approaches.
- Preference for family care and the ability to be actively involved in the child's care and therapies.
- Financial considerations, including cost and affordability of child care options.
- Challenges related to the child's unique needs, such as nonverbal communication, medical requirements, and behavioral issues, which may not be adequately addressed in standard child care settings.

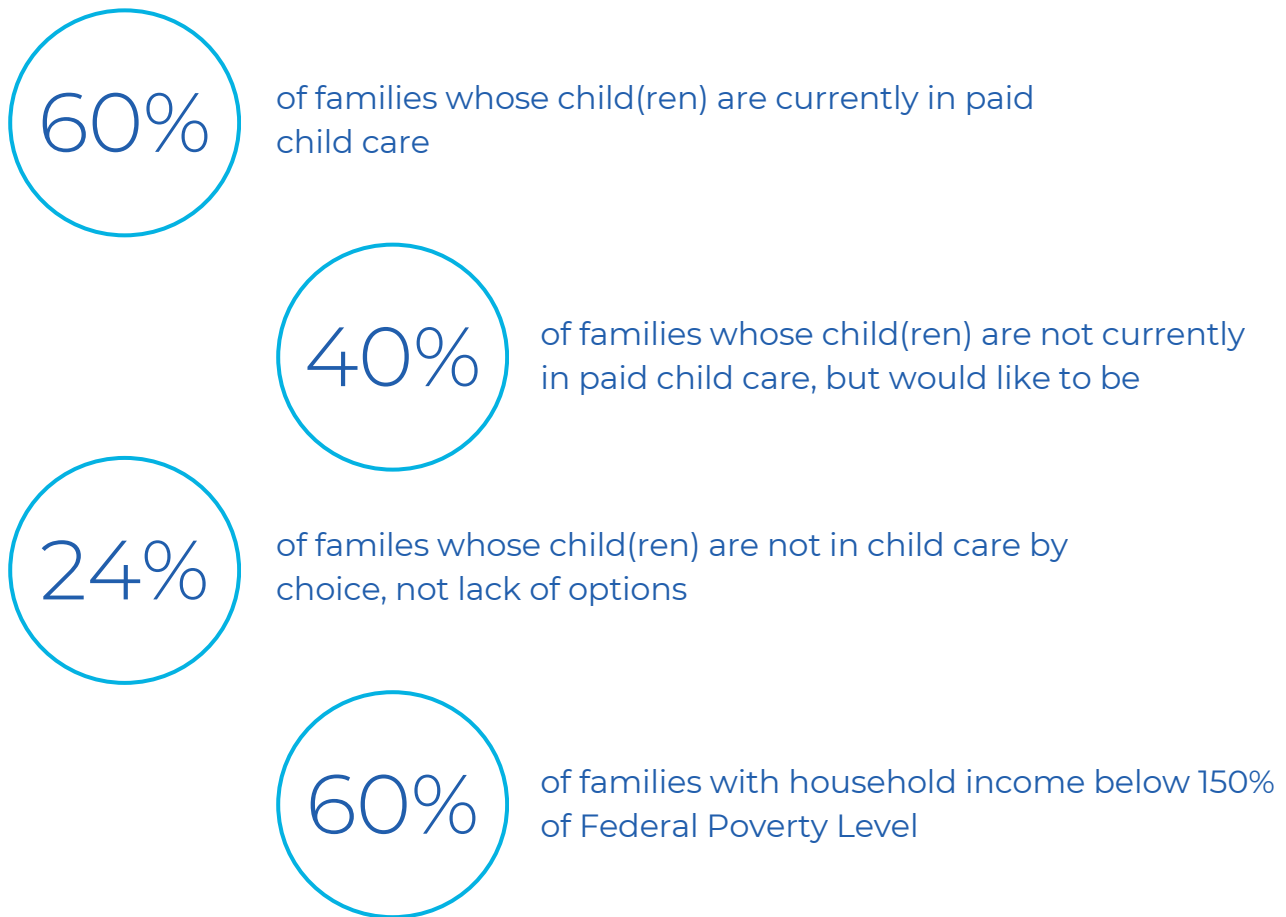


Survey Results

AWARENESS OF SPECIAL NEEDS ENHANCED RATE

Overall, about half of families indicated they are aware of the Publicly Funded Child Care and the Special Needs Enhanced Rate offered in Ohio.

Below is a breakdown, by various demographics, of those who are aware:



- More than 75% of families that are aware of the benefit sought to find out if they were eligible for the benefit.
- Those with household incomes above 150% of Federal Poverty Level were more likely to check their eligibility than those with household incomes below the threshold.
- Among those that are aware of the benefit, 80% of respondents indicated that their child care provider applied on their behalf.

Survey Results

Key Findings:

1. 53% of respondents said that their ability to work was either significantly or very significantly impacted due to lack of access to child care for their child with a developmental disability.
2. Roughly half of those who took the survey indicated they made less than 150% of the Federal Poverty Level, which is a household income of less than \$45,000 per year for a family of four. Those above that threshold do not currently qualify for any financial assistance.
3. 60% indicated that they have experienced a child care program saying-- directly or indirectly-- that they would not serve their child due to the child's needs associated with their developmental disability.
4. 70% indicated that they had to leave a child care provider and find a new one due to unmet needs.
5. 26% said their child wasn't in childcare, but that they want them to be and can't because of a lack of options for their child with a disability.
6. Families that are below 150% of the Federal Poverty Level were 12% higher to have experienced child care providers communicating- directly or indirectly- they couldn't provide the child care due to factors related to their developmental disability than families that were above 150% of the Federal Poverty Level.
7. (68.6% for Families above versus 56.6% for Families below 150% Federal Poverty Level)

Interview Process

DSACO has partnered with i3 Works, a data company out of Minnesota that specializes in working with non-profits, and assisted in designing our survey to help us understand families' needs regarding child care.

Focus

The survey is focused on the impact of child care on a family with a child with a developmental disability, the process of finding child care, how families become aware of public benefits, and child care for children with developmental disabilities over the age of twelve.

Methods

Through various organizational partners, we invited Ohio families who have a child with a developmental disability to participate in the interviews. We engaged with community stakeholders to identify people willing to share their experiences who met the qualifications, as defined in the survey, to provide feedback.

Results

Sixteen interviews were conducted. Of the sixteen respondents, information was gathered for eighteen children with developmental disabilities.

Respondent Data

Child's Age	#	%
Birth through 3	6	33.33%
4 through 5	4	22.22%
6 through 11	4	22.22%
12 through 17	4	22.22%
18 through 21	0	0.00%
22+	0	0.00%
Grand Total	18	100%

Survey Quotes

Prior to kids I worked a traditional job. I expected to step away for a while but had to step away permanently after having my son (with a developmental disability).

I just wish that it would be easier to find child care in general for children with disabilities.

Between hospitalization and appointments, jobs have fired me or let me go.

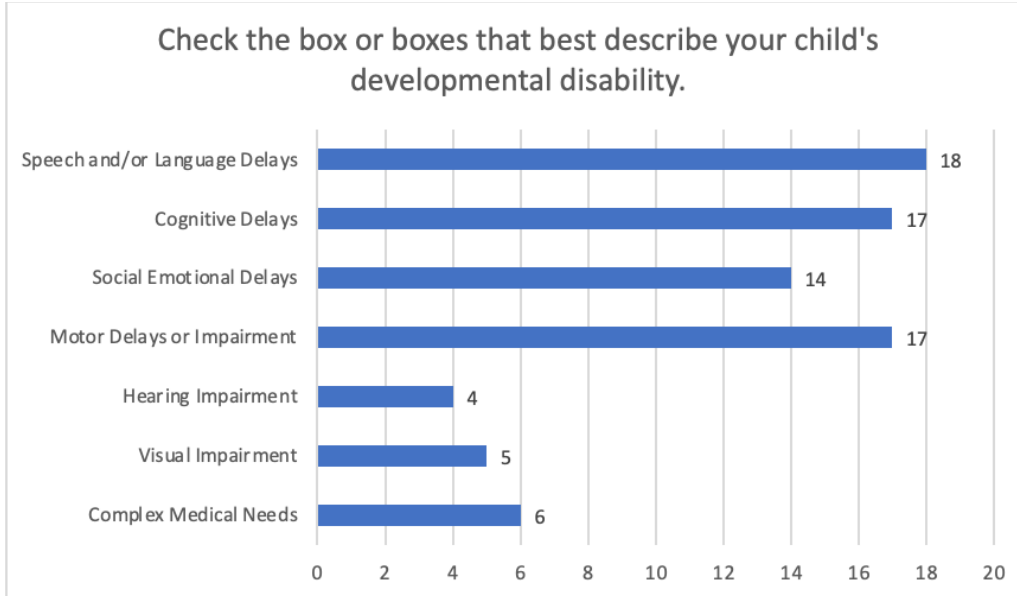
I wish there was something for him at his current age.

Strongly urge the (decision makers) to think about the needs of not only young kids but the kids who are a little older and have aged out of traditional child care center but are not old enough for adult programs.

I didn't (go about finding child care). Three different professionals told me there wouldn't be anything available locally. I was told nobody wants to do it because they don't feel like they could physically or emotionally (do it).

Potty trained always keeps our kids held back and that bothers me. It shouldn't keep them from being with their peers.

Interview Results



Key Findings:

1. Families often have to make special accommodations for child care providers to care for their child with a developmental disability.
2. 68.75% of interviewed respondents stated employment was impacted due to their child having a developmental disability.
3. 75% of interviewed respondents experienced perceived discrimination or negative attitudes from a child care provider or other parents because of their child's developmental disability.
4. 18.75% of interviewed respondents were aware of the public benefit.
5. Preferred communication methods when presenting available opportunities (like the public benefit) are print, email, social media, county boards of developmental disabilities, child care providers, and local or statewide family advocacy agencies.

Recommendations

After spending significant time learning and listening to the voices of families, we are grateful for the opportunity to share our recommendations that may lead to improved outcomes for families whose child has a developmental disability:

- ① Training and dollars to provide additional staff are needed to care for the complex needs of children with developmental disabilities. This investment will not only aid in the confidence of child care programs' staff but will also increase the confidence families have in current or potential child care programs.
- ② Evaluate the current Special Needs Enhanced Rate application process to consider having approval and funding move with the child should a family choose a new licensed child care program.
- ③ Evaluate licensure requirements for child care programs to open up access to families whose children with developmental disabilities are 12 and older.
- ④ Consider training or evaluate licensure requirements relating to toileting/potty training requirements of older children to address issues with lack of inclusion and lack of overall accessibility to licensed child care programs.
- ⑤ Consider financial assistance for families who have a child with a developmental disability, but who are above the current maximum 150% Federal Poverty Level requirement of the Special Needs Enhanced Rate, so that they can access higher-rated or higher-quality child care.
- ⑥ Evaluate opportunities for child care program endorsements to address key accessibility barriers such as behavior supports, medical needs, diapering/toileting, and physical accommodations to reduce the burden of family navigation based on their child's unique needs and child care priorities.

Conclusion

768 families in Ohio who have a child with a developmental disability have spoken about the unique challenges when it comes to child care. These families often need specialized care for their children, which can be challenging to find and can often come at a higher cost. The survey and interview opportunities gave families an opportunity to provide insight on their experiences with child care and communication preferences. Families are the best source of vital information to share with policymakers, family-focused organizations, and the community. Child care decisions impact all families, especially families with a child with a developmental disability.

Results of the Four Areas of Focus:

- Majority of respondents experienced perceived discrimination or negative attitudes from a child care provider or other parents because of their child's developmental disability.
- Child care decisions impact families personally and professionally, and the process of finding child care does not stop once a child care provider is selected as over 70% of families had to leave a provider due to unmet needs.
- Families prefer email, social media, and hearing from their local county board of developmental disabilities to learn about public benefits.
- Families with a child with a developmental disability over the age of 12 face even more barriers due to lack of child care providers providing care for children over the age of 12 and policies, like toileting/potty training requirements, that are less accessible.

Contact

DSACO

510 E. North Broadway St. Columbus, OH 43214
614-263-6020 | info@dscaco.net | dscaco.net

We thank you for affording us the opportunity to invest our time and energy into this important work!

Appendix 1

Survey Questions

Section	Question	Question Type
(A) Intro	Are you an Ohio resident?	Single Select
	How old is your child with a developmental disability?	Number
	Check the box or boxes that best describe your child's developmental disability.	Multiple Select
	Which of the following best describes you...Child is in child care, Child is not in child care, but would like to be, Child is not in child care by choice (Skip logic would begin)	Single Select
(B) Child is in child care	When looking for child care, approximately how many child care centers did you visit before you made your selection?	Single Select
	Were there any child care providers that communicated-directly or indirectly-they couldn't provide child care to your child due to factors related to their developmental disability?	Single Select
	What factors did the child care provider say they could not meet?	Multiple Select
	Have you ever had to switch child care providers because they were unable to meet your child's needs related to their developmental disability?	Single Select
	Have you ever experienced any perceived discrimination or negative attitudes from child care providers or other parents because of your child's developmental disability?	Single Select
(C) Child is not in child care, but would like to be	Is the child at home with a parent/guardian or with another family member?	Single Select
	Why is your child not in child care?	Multiple Select
	When looking for child care, approximately how many child care centers did you visit?	Single Select
	How did the lack of child care impact you and your family?	Multiple Select
	If you would like, please explain....	Open Text
	Were there any child care providers that stated they couldn't provide child care to your child due to factors related to their developmental disability?	Single Select
	Were there any child care providers that you felt would be unable to provide care for your child due to factors related to their developmental disability?	Single Select
(D) Child is not in child care by choice	What were factors that were important for you in deciding not to put your child in child care?	Open Text
	To what extent does your child have any needs (related to their developmental disability) that child care providers are unable to meet?	Likert
	To what extent has the need for child care impacted your ability to work a paid position or the position you have?	Likert

Appendix 1

Survey Questions

Section	Question	Section
(D) Child is not in child care by choice	What were factors that were important for you in deciding not to put your child in child care?	Open Text
	To what extent does your child have any needs (related to their developmental disability) that child care providers are unable to meet?	Likert
	To what extent has the need for child care impacted your ability to work a paid position or the position you have?	Likert
(E) Aware of public benefit	Are you aware there is a public benefit in Ohio called Publically Funded Child care for Children with Special Needs?...Aware of public benefit or not aware of public benefit (Skip logic would begin)	Single Select
	Did you seek to find out if you're eligible?	Single Select
	Did a provider apply on behalf of your child?	Single Select
	What did the provider require from you when applying for the benefit?	Open Text
	How satisfied were you with your experience of the application process as a whole?	Likert
	How were you made aware of your eligibility?	Multiple Select
(F) Not aware of public benefit	How do you prefer to learn about available opportunities?	Multiple Select
	How are you made aware of programs and opportunities that could benefit your family?	Multiple Select
Demographics	County of residence	Single Select
	How do you identify your race?	Multiple Select
	How do you identify your ethnicity?	Single Select
	How do you identify your gender?	Single Select
	What is the highest level of education you have completed?	Single Select
	How many adults live in your household?	Number
	How many dependent children live in your household?	Number
	Based on the chart above please select one of the following.	Single Select